

Family perceptions of quality of end of life in LGBTQ+ individuals: a comparative study

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Abstract

Background: Members of the lesbian, gay, bisexual, transgender, and queer community have encountered discrimination and stigmatization related to sexual orientation and/or gender identity both within healthcare establishments and in the larger community. Despite the literature describing inequities in healthcare, very little published research exists on the experiences of lesbian, gay, bisexual, transgender, and queer patients and family members in hospice care.

Methods: A quantitative comparative descriptive design explored the difference in end-of-life experiences between a lesbian, gay, bisexual, transgender, and queer and non-lesbian, gay, bisexual, transgender, and queer cohort. One hundred and twenty-two family members of individuals who have died while under hospice care in the past 5 years completed the Quality of Dying and Death Version 3.2a Family Member/Friend After-Death Self-Administered Questionnaire.

Results: Comparison of the experiences of the lesbian, gay, bisexual, transgender, and queer cohort ($n=56$) and non-LGBTQ cohort ($n=66$) yielded varying results, with the LGBTQ cohort experiencing lower quality end of life in some Quality of Dying and Death measures and no statistically significant difference from the non-LGBTQ cohort in others.

Discussion: The findings from this study in combination with previously published works on lesbian, gay, bisexual, transgender, and queer health support the position that hospice providers must take concrete steps to ensure that professional caregivers and office staff are qualified to meet the needs of this marginalized population.

Keywords: end of life, hospice, lesbian, gay, bisexual, transgender, and queer, palliative care

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Historically and contemporaneously, members of the lesbian, gay, bisexual, transgender, and queer (LGBTQ) community have encountered discrimination and stigmatization related to sexual orientation and/or gender identity both within healthcare establishments and in the larger community.^{1–10} While there have been recent gains in visibility of LGBTQ people, discrimination in health care persists.¹¹ These issues have engendered distrust and avoidance of healthcare providers by many members of the LGBTQ community,^{1,2,4–7,9,10,12,13} and inequities in health have led to the designation of the community as a health disparity population by the National Institutes of Health.¹⁴ Increasing barriers to access of care as a result of the COVID-19

pandemic will only compound inequities for the LGBTQ community.^{15,16}

Specific issues in end-of-life or palliative care for the LGBTQ population include stigma and associated stress, considerations in support systems (such as chosen families), advance care planning, and isolation.^{12,13,17,18} Providers must be knowledgeable about these issues and be intentional in their assessment and interventions. Staff who claim to treat patients without regard to their sexual orientation or gender identity, while well-meaning, may neglect to assess for the needs and concerns of the individual regarding end-of-life care, including the need to include the patient's family of choice in

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decision-making.¹⁹ As Acquaviva⁹ notes, “(b)eing inclusive is not the same as treating everyone the same” (p. xvi). End-of-life or palliative care for LGBTQ people must be inclusive; without inclusivity, a high-quality end-of-life experience is unlikely.

While increased attention has been given to LGBTQ end-of-life needs in recent years, much of the literature on the topic has been in the form of single-patient case studies, the need to educate providers on LGBTQ issues, and guidelines for practitioners (see Hinrichs and Christie,²⁰ Maingi and colleagues;²¹ and Sprik and Gentile²² for examples). Most research on LGBTQ end-of-life issues has centered on the fears of individuals regarding future care needs, not the experiences and perceptions of actual care received.¹³ Very little information has been published regarding the actual experiences of LGBTQ people in hospice care, or comparing LGBTQ experiences to the non-LGBTQ population.¹²

Recent work by Stein and colleagues²³ gathered information from more than 800 hospice and palliative care providers across multiple healthcare professions. Over half reported that lesbian, gay, or bisexual patients would encounter discrimination from providers; the percentage was even higher for transgender patients. Many had directly observed discrimination by providers toward LGBTQ patients and family members. Stein and colleagues’ work is an important piece in understanding LGBTQ hospice experiences, but additional perspectives are needed. This study aimed to provide more information to address the research gap¹² by examining end-of-life experiences from the perspective of family members, and comparing the experiences of LGBTQ people and non-LGBTQ people in hospice care. Obtaining information comparing LGBTQ experiences with non-LGBTQ experiences provides understanding of what disparities between groups exist; this is crucial to ensuring justice in healthcare.

Methods

Quantitative data collection in this study used Ruland and Moore’s Theory of the Peaceful End of Life. This theory proposes five concepts that contribute to a peaceful end-of-life experience: not being in pain, experience of comfort (i.e. the absence of unpleasant symptoms other than pain), experience of dignity/respect, being at peace, and closeness to significant others/persons who care.²⁴ These five concepts were linked with

items on the Quality of Dying and Death (QODD) Version 3.2a Family Member/Friend After-Death Self-Administered Questionnaire (QODD3.2-FAM). This instrument, one of several QODD instruments available from the University of Washington, was used to measure the perceptions of family members regarding the quality of death and dying of a loved one. The QODD instruments have been widely used in end-of-life research with family members and healthcare professionals.^{25–30} Permission was granted regarding the alteration of pronouns in survey items to more accurately reflect the diversity of the LGBTQ community (e.g. his/her/their, him/her/them, she/he/they).

Concepts on the QODD3.2FAM are measured in 22 items (QODD-22), with respondents rating the quality of an aspect of dying and death on a 0–10 scale. A final item assesses overall quality of dying and death (QOD-1). In this study, Cronbach’s alpha was calculated for the QODD-22 alone (.89 for total sample, .93 for LGBTQ group, .84 for non-LGBTQ group), as well as for the QODD-22 and the QOD-1 combined (.89 for total sample, .93 for LGBTQ group, .85 for non-LGBTQ group).

Demographic items on the survey included: sexual orientation and gender identity of the deceased, relationship of the respondent to the deceased, age, insurance status, location of death, income, and hospice provider information. This information was used to separate responses into LGBTQ and non-LGBTQ groups, and to compare demographics between groups to assess for factors that may account for differences in quality of dying and death. Due to the focus of this study on the experiences of the individual enrolled in hospice care and concerns of survey fatigue, demographic information from the survey respondent was limited to their relationship to the deceased.

This study used a comparative descriptive design to determine whether differences exist between family members’ perceived quality of end-of-life experiences of LGBTQ and heterosexual, cisgender individuals at the end of life. This type of non-experimental design is useful when it is not possible to alter the independent variable;³¹ however, the nature of non-experimental research poses some threats to validity. Non-experimental designs do not allow random assignment to groups, which can be useful in controlling for extraneous variables that may impact study results. Random sampling

was deemed too difficult to locate a sufficient number of individuals, as the study was seeking a minority within a minority. The absence of random sampling leads to selection bias as an internal threat to validity and difficulty generalizing the results to a wider population, a threat to external validity.³²

This study was submitted to the University of Indianapolis Institutional Review Board by the author. Once approval was obtained from the University of Indianapolis, the author sought approval from the Catholic University of America. The author received permission for a waiver of signed informed consent to minimize the link between individual participants and the study. The informed consent document noted emotional distress was a possible outcome of participation in the study, and provided information regarding mental health services, including national hotline numbers. Due to the anonymous nature of the study, follow-up with participants to assess for emotional distress was not feasible.

Recruitment was conducted using multiple venues to contact potential participants. Requests to service providers and social support groups, including those targeting the LGBTQ population and general groups aimed at older adults or individuals who have lost loved ones, to post study information was useful for recruitment, as was online advertisements on social networking sites (e.g. Facebook), message boards, or websites containing resources for bereaved family members. Attendance at events such as local Pride festivals provided an opportunity to connect with the LGBTQ population of interest, both by providing flyers to individuals attending the festival and speaking to representatives of local organizations with booths at the event.

Inclusion criteria allowed for the participation of any individual over the age of 18 who had lost a close family member, also over the age of 18, under hospice care in the preceding 5 years. Close family members needed not be blood relatives or individuals legally recognized as related to the deceased, as a number of LGBTQ individuals rely on informal families of choice to provide support.^{33–36} Participants were required to be able to read, write, and understand English. Due to the nature of the items regarding the quality of death and dying, otherwise eligible individuals who were not present with the deceased during the last week of life were excluded from participation in this study. A small monetary honorarium (\$15

Amazon gift card) was provided as compensation to subjects for time spent participating. Funding for the gift card was obtained via the University of Indianapolis Faculty Scholarship Grant program.

Results

A total of 122 participants were included in the final sample for this study. The non-LGBTQ group ($n = 66$) was slightly larger than the LGBTQ group ($n = 56$); however, both groups exceeded the minimum group size of 51 established by *a priori* power analysis. The LGBTQ group was comprised of data from: 28 gay men, 19 lesbians, 8 bisexual people (1 of whom was also queer), and 4 transgender people (two of whom were also bisexual, and one who was a lesbian). Most respondents were the child/stepchild/child-in-law (24%), niece or nephew (20%), grandchild/grandchild-in-law (16%), or spouse (12%) of the deceased.

There were significant differences in age, income, and primary medical diagnosis between groups (Table 1), but no difference in race/ethnicity, insurance status, engagement with Veterans' Affairs services, and population density in the area where hospice care was received. While individuals from the LGBTQ group were more likely to die in the hospital than those who were not LGBTQ ($p = .003$), the length of time from diagnosis to death and length of time in hospice was not significantly different between the groups, nor was the likelihood of dying in a preferred location different. A higher percentage of LGBTQ cases occurred in the Western Region of the United States, while non-LGBTQ cases concentrated in the Midwest Region ($p = .024$).

Means and medians for all QODD-22 items were calculated for the entire sample, and for each group separately. While medians and interquartile ranges are preferred measures of central tendency when data are not normally distributed, as was the case in this study for individual QODD-22 items, the median of nearly all (17 of 22) QODD-22 scores for the LGBTQ group was 7, making it difficult to distinguish between highest and lowest rated areas. Therefore, the means and standard deviations for scores on QODD-22 items are reported in this study.

Fifteen items had a higher median score in the non-LGBTQ group. Mean scores were higher in the non-LGBTQ group on 14 items. These

Table 1. Comparison of demographics between groups.

Variable	LGBTQ	non-LGBTQ	<i>p</i> value
Age (years) ^a	57 (21)	76 (19)	<0.001
Income ^a	\$40,001–\$75,000	\$25,001–\$40,000	0.004
Race ^b			
White/Caucasian, not Latinx	42	58	0.065
Not White/Caucasian	14	8	$\chi^2=3.4$
Insurance ^b			
Private insurance	25	27	0.827
Other insurance	29	34	$\chi^2=0.05$
Primary medical diagnosis			
Cancer diagnosis	26	31	0.014
Non-cancer diagnosis	10	35	$\chi^2=6.03$
LGBTQ, lesbian, gay, bisexual, transgender, and queer.			
^a Median (Interquartile range).			
^b Frequencies.			

results indicate a higher quality end of life for the non-LGBTQ group. Of note, the top 11 QODD-22 means in the non-LGBTQ group were greater than the single highest QODD-22 mean in the LGBTQ group (Table 2).

Total QODD-22 scores were calculated for all cases per the instructions of Glavan and colleagues,²⁸ with the average of all part b items completed multiplied by 10. An independent *t*-test was used to compare the difference between groups on the QODD-22 items. The results from the independent *t* test did not indicate a statistically significant difference between the LGBTQ and non-LGBTQ group on total QODD-22 score ($p=0.383$).

The QOD-1, the single item asking the respondent to rate the overall quality of their loved one's death, was answered by 118 of the 122 total respondents. As the assumptions for parametric testing were not met, the difference in QOD-1 scores between the LGBTQ and non-LGBTQ group was analyzed using a Mann–Whitney *U*-Test. The mean rank of the LGBTQ group and non-LGBTQ group were significantly different (52.13 versus 65.30, respectively, $p=0.035$). The effect size was small ($r=-0.19$).

Discussion

The aim of this study was to compare the experiences of LGBTQ people and non-LGBTQ people at the end of life based on the perspective of family members of those who died under hospice care. There were two different quantitative measures of overall quality of dying and death in this study, the QODD-22 total score and the QOD-1 score. While the single item QOD-1 was significantly lower in the LGBTQ cohort, this was not the case for the QODD-22 total score. Despite the top 11 QODD-22 individual item means in the non-LGBTQ group being higher than the top QODD-22 item mean in the LGBTQ group, there was no statistically significant difference between groups on the QODD-22 total score. This is likely a result of excessively low scores on a few QODD-22 items in the non-LGBTQ cohort.

The discrepancy between the two measures of overall quality of dying and death raises the concern that the instrument may not be valid in the LGBTQ population. Although the reliability of the instrument for the LGBTQ cohort in this study was acceptable, there may be one or more important aspects of the LGBTQ end-of-life experience that are not adequately captured by the QODD-22. While the qualitative component

Table 2. Means and standard deviations, QODD-22 items.

QODD-22 item	LGBTQ <i>M (SD)</i>	Non-LGBTQ <i>M (SD)</i>	Total sample <i>M (SD)</i>
Pain control	6.67 (1.94)	6.29 (2.41)	6.46 (2.21)
Control of surroundings	6.29 (2.42)	5.47 (3.03)	5.84 (2.79)
Feed self	6.07 (2.49)	4.97 (3.13)	5.48 (2.89)
Breathe comfortably	6.13 (2.24)	5.36 (3.38)	5.71 (2.93)
At peace	6.83 (2.45)	6.23 (3.12)	6.5 (2.84)
Fear (Unafraid)	6.39 (2.44)	6.64 (3.11)	6.52 (2.8)
Laugh/smile	6.09 (2.38)	5.79 (2.84)	5.93 (2.63)
Dignity/respect	6.83 (1.82)	6.08 (2.88)	6.42 (2.48)
Family time	7.46 (1.88)	8.78 (1.78)	8.17 (1.94)
Time alone	6.65 (2.45)	8.06 (2.4)	7.41 (2.52)
Hug/tough	7.59 (1.66)	9.09 (1.44)	8.4 (1.71)
Cost	7.42 (2.4)	7.8 (2.57)	7.62 (2.48)
Goodbye	6.7 (2.47)	7 (3.01)	6.86 (2.76)
Clear up bad feelings	6.74 (2.06)	7.14 (3.09)	6.91 (2.55)
Religious advisor visit	7.02 (2.09)	8.18 (2.15)	7.65 (2.19)
Religious service	7.02 (2.19)	7.75 (2.41)	7.41 (2.33)
Ventilator	7.65 (2.08)	7.81 (2.49)	7.74 (2.3)
Dialysis	7.45 (2.44)	8.11 (2.19)	7.82 (2.32)
Funeral arrangements	7.25 (1.96)	7.05 (3.25)	7.14 (2.72)
EOL plans/wishes quality	7.2 (2.22)	8.14 (2.74)	7.7 (2.54)
Presence of others at death	7.45 (2.06)	8.18 (2.32)	7.84 (2.23)
Consciousness (state) at death	7.09 (2.17)	7.79 (2.52)	7.46 (2.38)

LGBTQ, lesbian, gay, bisexual, transgender, and queer; QODD, Quality of Dying and Death; SD, standard deviation; EOL, End of life.

of this study (not reported in this manuscript) does not suggest additional themes that are crucial to understanding LGBTQ end of life were not included on the QODD-22, future research may require the creation of an instrument for this specific population. Creation of one or more instruments for studying LGBTQ end of life should focus on the input of members of the LGBTQ community. Given the information reported by Stein and colleagues²³ about the prevalence of discrimination by hospice and palliative care providers toward LGBTQ clients,

with increased discrimination toward transgender clients particularly, a separate instrument specifically for transgender clients may be important to understanding the specific experiences of this segment of the LGBTQ community.

Other possible reasons for the discrepancy between QODD-22 total scores and QOD-1 scores lie in the age and income levels of the sample. Although no scientifically based demographic information could be located on LGBTQ people in the United States, the median age of LGBTQ decedents in

this study was well below that of the United States population as a whole, currently 78.6 years.³⁷ Evidence from the literature is conflicting regarding whether or not this difference could have contributed to the differences seen in quality of dying and death. One study found that respondents whose loved one was 60 years of age or older at the time of death were more likely to report that their loved one had experienced a good death than those whose loved one was less than 60 years of age.³⁸ A separate review of the literature concluded that elderly patients were more likely to have factors that may detract from a high-quality end-of-life experience, such as higher symptom burden and poor advance care planning.³⁹ Conversely, Cagle and colleagues⁴⁰ did not find older adults were more likely to experience a good death, though their study was not limited to hospice-involved cases. Whether or not age is a significant contributing factor to the quality of dying and death warrants further study. In addition, a comparison of the life expectancy of the collective LGBTQ population in the United States with the general population and further exploration of differences in life expectancy based on gender identity, sexual orientation, socioeconomic status, race, and other demographic factors should be undertaken to discern differences between groups.

Despite evidence that in the United States LGBTQ people are more likely to have an income under \$24,000 annually than non-LGBTQ people (25% vs 18%, respectively),⁴¹ the LGBTQ decedents in this study had a higher median annual income than the non-LGBTQ decedents. It should be noted that the numbers cited above⁴¹ reflect the socioeconomic status of the entire community; previous work has found that lesbian and bisexual women, LGBTQ people of color, transgender people, and LGBTQ youth may be more susceptible to poverty than the wider LGBTQ community.⁴² Previous studies detailing the association between socioeconomic status and quality of dying and death support the expectation that the LGBTQ group in this study should have reported an overall higher quality of dying and death. For example, Nayar and colleagues⁴³ found a statistically significant correlation between socioeconomic status and late enrollment in hospice care in a study of elderly Medicare patients with lung cancer in which late hospice enrollment was considered a marker of poor end-of-life care. This supports a negative association between socioeconomic status and quality of end of life. Hughes also concluded that those with

lower income are at higher risk for a low-quality death.⁴⁴

While it would be expected, based on socioeconomic status, that LGBTQ individuals in this study would receive better care and subsequently experience a higher quality end of life, the responses on the QOD-1 item do not support this conclusion. In this study, loved ones of non-LGBTQ decedents reported high-quality dying and death, despite lower annual income. Given the information from the Williams Institute regarding the socioeconomic status of LGBTQ people in the United States,⁴¹ evidence suggesting that socioeconomic status contributes to quality of end-of-life experiences, it is hypothesized that a sample controlled for socioeconomic status would find a greater disparity in end of life experiences for LGBTQ individuals.

Implications for practice

Evidence from the literature demonstrates that LGBTQ individuals have concerns about access to care and discrimination at the end of life. The findings from this study in combination with previously published works on LGBTQ health support the position that hospice providers must take concrete steps to ensure that professional caregivers and office staff are qualified to meet the needs of this population.

Education. Education for providers, clients, and family members is necessary to address gaps in quality of care. Any professional who interacts with clients, including administrative staff, must be required to attend competency training.²¹ Those who provide direct care, such as physicians, nurses, social workers, and nursing aides should also receive additional in-depth education on the impact of discrimination on LGBTQ health.²¹ Educational materials developed for client distribution should include information specific to LGBTQ clients and caregivers, including LGBTQ-specific support groups, if available.^{21,45} Clients who do not have a legally married partner, or who rely on legally unrecognized families of choice for support, must be educated on the importance of advance directives to establish decision-making responsibilities prior to incapacitation.^{21,45}

Policy and administration. To signal to potential clients and family members that a hospice provider organization is welcoming to LGBTQ clients and

families, administrators should ensure that the organization's non-discrimination statement is inclusive and easily located on websites, in client education materials, and within office and/or care spaces. This statement must explicitly include sexual orientation, gender identity, and gender expression.^{21,45} A stated commitment to non-discrimination is important, but a statement alone is insufficient to ensure equitable treatment of LGBTQ clients. Commitment to equity for the LGBTQ community must be a commitment to ensure inclusion at all levels of the organization.

Commitment to LGBTQ equity in hospice goes beyond supporting clients and families who are receiving care. As noted by Acquaviva, “[f]or [an] organization to be a place where LGBTQ individuals and their families feel safe and comfortable accessing services, it needs to be a place where LGBTQ employees feel safe, comfortable, and valued” (p. 214).⁹ Acquaviva recommends examining a number of policies and benefits to ensure alignment with best practices from the Human Rights Campaign for promoting LGBTQ equity in the workplace.⁹ This includes equal coverage for same-sex partners in insurance, retirement, and leave benefits and insurance benefits for transgender individuals who need health care services to medically transition. Not only do organizations need to hire LGBTQ individuals as employees, they must ensure that there is representation from the LGBTQ community in management and administration positions.⁹ Engaging LGBTQ employees from all levels of an organization to create an inclusive environment for clients, caregivers, and staff will assist in addressing problems and barriers to care that may have been previously unknown to administration.

While the education, policy, and administrative actions outlined in this section alone will not ensure high-quality end-of-life experiences for LGBTQ people, they would promote a basic understanding of the needs of the community and, in many regions, are relatively easy actions to undertake. Efforts to solve LGBTQ health disparities must go beyond one-time training and policies. Truly addressing the health disparities of the LGBTQ community and ensuring that care provided is consistently inclusive and responsive will require a shift in the ways care is given and the attitudes of those who provide it. Organizations must commit to making LGBTQ-inclusive care a priority, and support their commitment financially.

In areas of the world where being LGBTQ is criminalized, additional care is warranted in collecting and documenting information on sexual orientation and gender identity, and in creating spaces that are welcoming and inclusive. As a United States-based researcher, the author does not presume expertise in the needs of those living in nations where the legacy of colonialization continues to uphold codified violence against the LGBTQ community. Even in the United States, where the Supreme Court decriminalized gay and lesbian relationships almost 20 years ago, policies continue to prioritize heterosexual, cisgender people over LGBTQ people. The author echoes the recommendations of Harding and colleagues¹⁵ to advocate for an end to policies that discriminate against and criminalize LGBTQ people, and calls on heterosexual, cisgender allies who occupy positions of safety to use their privilege in this work.

Future research

While the results of this study do not conclusively demonstrate lower quality of dying and death in the LGBTQ cohort across all measures, they do show that further study is warranted to examine hospice experiences in this population. Unfortunately, as noted previously, the hidden nature of this population makes large-scale probability samples difficult. Including demographic information about sexual orientation and gender identity in client charts and data registries would assist researchers in better understanding the end-of-life experiences of LGBTQ clients and family members.²¹ Collecting information on sexual orientation and gender identity in all studies examining hospice and end of life, regardless of whether the focus of the study is specifically aimed at understanding LGBTQ experiences, will also further knowledge in this area.²²

In addition to collecting sexual orientation and gender identity data in all studies focused on hospice care and end of life, more studies aimed specifically at LGBTQ experiences at the end of life are needed to gain perspective on the current status of hospice care and test interventions designed to promote high-quality hospice care for this population. Qualitative and quantitative work may be used to ascertain experiences of those currently in hospice care and their families, with special care to include individuals of all queer identities and those living at the intersections of marginalized gender, race, disability, and socioeconomic

statuses. Such work must be careful to distinguish between the experiences and needs of privileged identities within the LGBTQ community (such as those of white, cisgender, affluent, able-bodied gay men) and those of more marginalized identities. It is likely that the experiences of those in the community with more privilege will be vastly different from the experiences of those without. Research that samples disproportionately from these privileged voices will be incomplete and ill-suited for use in improving care for the community at-large.

Further comparative studies should test for differences in quality of dying and death for LGBTQ clients who receive care from hospice organizations using best practices such as inclusive non-discrimination statements and mandatory staff training with those who receive care from organizations that do not incorporate best practices. These studies should not only include measurements from family members and caregivers after death but must involve the participation of individuals currently enrolled in hospice care to obtain more comprehensive data about the experience. Results may provide needed support to convince organizations that have not adopted best practices to do so, or may reveal that these interventions are insufficient to promote a high-quality end-of-life experience to the LGBTQ community.

In addition, data should be collected from hospice providers at all levels to determine healthcare workers' perspectives on the quality of end-of-life care received by LGBTQ individuals and their families. Information about the attitudes of hospice providers toward the community as a whole, and subsets of the community, such as transgender individuals, may inform future interventions aimed at helping the population achieve a high-quality dying experience. Participants may also be able to provide insight into systemic barriers faced by the community in accessing hospice care or engaging with hospice providers. Ideally, such research would include the views of both LGBTQ and non-LGBTQ healthcare professionals.

Information derived from the aforementioned research should be used to inform the development of interventions to improve the quality of end-of-life care received by LGBTQ individuals enrolled in hospice care. The consideration of perspectives of those enrolled in services, their family members, caregivers, and healthcare

providers can provide robust support both in crafting interventions and implementing them appropriately. Data collected from before and after such interventions are implemented are crucial to supporting their efficacy or revealing a need for additional work in this area. Ultimately, the goal of research in this area is aimed at the creation of effective interventions delivered both at the point of care and away from the bedside to promote positive end-of-life experiences for the LGBTQ community.

Limitations

The primary limitation of this study, as predicted prior to data collection, lies in the sample. Not only was the sample for this study recruited through non-probability methods, the final cohort was overwhelmingly white, non-Latinx, and insured. In addition, the median income of the LGBTQ cohort was relatively high and the median age at death low. As a result, the experiences of those in the LGBTQ community most at risk for increased marginalization due to race, income, insurance status, and age may not be well represented in this study. Future research focusing on the experiences of people of color, those living near or below the poverty line, those who are uninsured or underinsured, and those who are older is needed to gain a more robust understanding of LGBTQ end-of-life experiences.

As discussed previously, the instrumentation utilized for data collection may not adequately capture LGBTQ experiences at the end of life. The discrepancy between the two measures of overall quality of dying and death (the QODD-22 total score and the QOD-1) raises concern that the Quality of Dying and Death (QODD) Version 3.2a Family Member/Friend After-Death Self-Administered Questionnaire may not be valid in the LGBTQ population. Future research aimed at developing and validating an instrument for measuring quality of dying and death specifically in LGBTQ individuals may be appropriate.

Summary

The purpose of this study was to ascertain the quality of death and dying of LGBTQ individuals and non-LGBTQ individuals as perceived by close family members of deceased patients and compare experiences between the two groups. Study findings indicate there are some differences

in the ways that LGBTQ and non-LGBTQ individuals experience end of life in hospice care. However, whether or not the overall quality of dying and death is different between the groups is unclear, with various measurements indicating either a worse experience for the LGBTQ population or no difference between groups. It may be that the relatively privileged status of many participants in the study (as predominantly white, non-Latinx, and insured) obscured the reality of those in the community who experience greater marginalization.

Further research is necessary to better understand the impact of sexual orientation and gender identity on the quality of end-of-life experiences, particularly when sexual orientation and/or gender identity intersect with race, socioeconomic status, age, gender, or other marginalized identities. Additional research is needed to develop and test interventions to promote high-quality end-of-life care among the LGBTQ community. Until such a time as these interventions can be developed, implemented, and have their impact measured, however, all hospice providers should consider the unique needs of the LGBTQ community in end-of-life care and undertake actions to promote high-quality care by providers that understand the LGBTQ community. This should, at a minimum, include adherence to best practices such as mandatory staff training, inclusive non-discrimination statements, and ensuring hospice organizations are welcoming to LGBTQ employees.

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